Dear Alyce England and Dr Rasool,

May I please clarify, particularly with the kind Dr Rasool, John's current medication and current blood sodium and haemoglobin levels, since some of the current prescription has provably (see below) caused all of his hospitalised collapses and dizziness via sodium, potassium and iron issues caused by medications, and we have been into this three times over the past year. John's low blood haemoglobin and low blood sodium cause dizziness that is artificial and is mistaken for frailty, which affects physiotherapists ability assess his ability to stand up without dizziness:

Summary of consultant's reports on privately diagnosed collapse causes and balance problems based on NHS-provided basic laboratory data for

JOHN COOK b. 30/06/1933, NHS No. 4129440845

Covering: August 2020-April 2021: summary by Ann Cook, retired RGN, 2 April 2021

John's most recent emergency admission prior to this one was for similar reasons that John is now lying in a bed and not walking competently, and it was confined to the EAU at Colchester Hospital and lasted just 2 days, 15 Dec – 17 Dec 2020.

The 6-pages long Colchester Hospital EAU Transfer of Care (Discharge Summary) states on page 3 that John's sodium level was 127 on 15 Dec 2020 at 9pm, very close to the 125 mEq/litre N.I.C.E. criterion for collapse and emergency NHS re-admission.

This is also almost exactly the same as the figure of 128 when he was discharged from Tiptree Ward by Dr Nadeem Aftab (Geriatric medicine) on 10 September 2020 with his Transfer of Care (Discharge Summary) report dated that day stating his sodium on discharge had only been increased from 114 mEq/litre on admission to 128 mEq/litre on discharge, still very close to the 125 mEq/litre N.I.C.E. criterion for collapse and emergency NHS re-admission.

This proves that my calculation (appended in full below) that John personally needs 1 gram of salt per litre of water to stabilise his sodium has worked since 10 September: the sodium level only changed from 128 on 10 September 2020 to 127 on 15 Dec 2020. However, he needs a slight increase beyond that 1 gram NaCl/litre to bring his sodium up from 127 or 128 to the normal of about 140 where he would be OK.

Page 4 of the Colchester Hospital EAU Transfer of Care (Discharge Summary) states that John's red cell haemoglobin at 9pm on 15 December 2020 was 94 g/L. The normal range is 130-180 in males, so John was extremely anaemic in addition to having a 128 sodium level, near the NICE collapse criterion of 125.

Therefore we know for certain that blood loss induced anaemia and hyponatraemia have both caused John oxygen insufficiency faints upon standing in the past, as well as some of other medication that reduces blood pressure by increasing blood potassium levels. Iron infusion or injection or a large vitamin B{***12***} injection to facilitate iron absorption into haemoglobin (likewise vitamin D allows calcium absorption) might be tried? Last Friday week my son was told by a nurse a doctor has requested a B{***12***} injection for John, but it was cancelled for some reason (maybe slow action?).

The summary of data below includes where stated reports I have privately commissioned from specialists and so it may not be accessible in the NHS medical history database on this patient, because private medical information including blood pressure measurements and privately paid for qualified medical consultant reports by Anne Glynn Clinical Specialist Physiotherapist MCSP HPC Registered PH36382 and consultant Mr Maheshwar FRCS (a large number of documents which can be supplied in full if necessary) are pertinent to all three recent emergency hospitalisation collapses of John Cook within the past year. All were caused principally by low sodium and low haemoglobin:

1. JOHN’S FIRST EMERGENCY NHS “COLLAPSE” ADMISSION:

21 August 2020 - John’s first passive “collapse” (not causing injury but requiring hospitalisation for loss of coordination) was less than one year ago. Hyponatraemia made him completely unable to even stand up for one second since he lost his mental ability to control his limbs including his arms, but had normal blood pressure (120/65) and pulse (76). He had not had a fall or physical injury. The day before he had walked up and down the 12 steps of the stairs to bed as usual, without a fall.

John’s GP, Dr Kumar (Highwoods Surgery), was unavailable and due to pandemic pressures on the NHS, John was home bed nursed for 6 days waiting for a phone call from a GP, unable to get out of bed or move a limb. GP Dr Suresh visited on 27 August 2020, was unable to diagnose the cause or prescribe solutions, so arranged immediate hospital admission for tests.

28 August 2020: Tiptree Ward diagnosed acute hyponatraemia/low sodium of 114 mEq/litre on admission sampling, 27 August 2019, far below the N.I.C.E. criterion of 125 mEq/litre for hyponatraemia collapse and admission to hospital (normal or ideal is about 135-145mEq/litre). This NICE concentration threshold is irrespective of age. He was discharged by Dr Nadeem Aftab (Geriatric medicine) of Tiptree Ward on 10 September 2020 with his Transfer of Care (Discharge Summary) report dated that day stating his sodium on discharge had only been increased from 114 mEq/litre on admission to 128 mEq/litre on discharge, still very close to the 125 mEq/litre N.I.C.E. criterion for collapse and emergency NHS re-admission.

I calculated John’s correct daily sodium intake to prevent further collapses in the future to be 2g salt per day per 2 litres of daily water intake and excretion (or 1 gram of salt per litre of drinking water, palatable contrasted to the 35g in a litre of seawater). This amounts to four times his normal 0.5g daily salt sprinkling on meals, and the full calculation of this 2g/daily salt intake requirement is appended (it begins with John’s officially measured NHS sodium level in mEq/litre and uses that with

John's body weight to derive the necessary intake as 1 gram per litre of salt intake). This exactly compensates for the sodium excretion of sodium when 2 litres daily water intake needed to prevent kidney infections and blockage from John's large staghorn kidney stones. We twice-daily monitored & home recorded his blood pressure & pulse to ensure no rise due to high sodium. Previously John had only 0.5g daily sodium intake from salt in food, so there had been a serious net sodium loss causing an expensive NHS bed blocking collapse. 1g salt added per litre of water intake, cheaply and safely stopped hyponatraemia, restoring his nervous system.

2. JOHN'S SECOND EMERGENCY NHS ADMISSION: 28 Nov 2020 11pm

This NHS hospitalisation from 28 November 2020-8 December 2020 was diagnosed by Ann Cook RGN (retired) as medication-induced hyperkalemia (high blood potassium, causing low blood pressure since potassium dilates veins) which induced hypotension (low blood pressure of 105/60 on a home blood pressure monitor) in conjunction with iron shortage anaemia, causing a collapse and fall.

The anaemia was observed first as chronic loss of over 10ml/day as proved by photos emailed to Highwoods Surgery of both urinary tract bleeding and skin bleeding from John's allergy to apixaban which the GP has not switched for an alternative.

The GP also kept John on several medications causing John's very low blood pressure, nicorandil, ramipril and even John's kidney antibiotic trimethoprim all increased his blood potassium level to dilate veils, thus decreasing blood pressure, causing him to faint with 105/60 blood pressure. It was still hypotension when paramedics arrived.

Trimethoprim just by itself caused very high serum potassium levels about 5mmol/L in 50% of patients on Trimethoprim, near the 5.5mmol/L hyperkalemia level, as reported in: "Renal mechanism of trimethoprim-induced hyperkalemia", Annals of Internal Medicine, 15 Aug 1995, v119, issue 4, pages 296-301, available at: https://pubmed.ncbi.nlm.nih.gov/8328738/

So that paper shows John's prophylactic Trimethoprim to prevent kidney infection contributed to John's hyperkalemia and therefore his hypotension, making him fall! There are other antibiotics.

In addition, since discharge on 10 September 2020 John has been losing an average of about 40ml/day blood loss from both urinary bleeding and skin bleeding from John's allergy – repeated telephone calls and emails we have saved that we sent to the GPs at Highwoods Surgery during the pandemic, containing photos of John's bleeding. Chronic bleeding at a rate greater than blood is replenished causes anaemia. Calculation: textbook red blood cells have 120 days mean life, and the patient contains 5 litres of blood of which 1 litre is rec cells /RBCs, so the daily RBC loss from normal expiration of RBCs is 1/120 litres/day or about 8ml/day, which is replaced naturally by the bone marrow supply of new RBCs. aAdditional 10ml/daily losses in bleeding in urine and more in blood soaked vests you could squeeze blood out of and measure in a measuring cup, produces acute anaemia within 4 months. The total RBC loss in John is then 10 + 8 = 18ml/day, twice the maximum production.

The NHS Discharge Summary for John’s 28 Nov – 8 Dec 2020 admission to Birch Ward (consultant Dr Ajith Pillai) agreed with my blood pressure monitor and observed bleeding, diagnosing postural hypotension (fall when standing due to low blood pressure) and anaemia. It also changed John’s medication, stopping the prescriptions for blood potassium boosters ramipril and niorandil, and also the beta blocker sotalol which was slowing John’s pulse to below 69 which reduced oxygen to the brain causing dizziness. It also helped by introducing Furosemide, and sodium bicarbonate ear drops but continued with apixaban to which John has a skin bleeding allergy and urinary bleeding. It instead prescribed Dermol and Cetraben cream for skin bleeding. Before Apixaban John was on Warfarin which is an alternative that caused no skin bleeding, but this was stopped due to the weekly blood tests needed with Warfarin. But there are several alternatives that safely reduce platelet clotting and are nearly as effective in large trials (John was on 75mg daily aspirin prior to Warfarin).

3. JOHN’S THIRD EMERGENCY NHS ADMISSION: 15 Dec 2020 9pm

This is the really vital collapse and fall for understanding the mechanism for John’s dizziness and collapses, and the emergency admission was confined to the EAU at Colchester Hospital and lasted just 2 days, 15 Dec – 17 Dec 2020.

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Therefore we know for certain that blood loss induced anaemia and hyponatraemia have both caused John oxygen insufficiency faints upon standing in the past, as well as some of other medication that reduces blood pressure by increasing blood potassium levels. John normally insists on taking all his medication with a religious respect for doctors, and refuses to appreciate that during the pandemic they do not have the time to read all his lengthy reports. I hope that the medical summary below will focus your attention on John's blood haemoglobin and blood sodium as physiotherapists assess his ability to stand up without dizziness.

ANNEX

John Cook's (born 30/06/33, NHS number 4129440845) estimated extra required salt intake of 2.2g/day needed to prevent any further acute hyponatraemia collapses/falls, calculated from Colchester Hospital's blood sodium report (by Ann Cook, SRN (retired), January 2021)

John B. Cook sodium level (on admission
emergency Colchester Hospital on 27 August 2020):

114 mEq/litre (very low), causing collapse.

N.I.C.E. criterion of hyponatraemia admission to hospital (collapse):

125 mEq/litre.

Normal or ideal sodium level: 135-145 mEq/litre (NHS website).

Hyponatremia: low blood sodium concentration (below 135 mEq/litre)
A normal blood sodium level is between 135 and 145 milliequivalents per liter (mEq/L). Hyponatremia occurs when the sodium in blood falls below 135 mEq/L. Kidney stones cause the retention of excess fluid in the body, diluting the sodium to low concentration, causing dizziness, cramps, irregular heartbeat etc.

Sodium blood level units conversion factor: 1mEq of sodium-23 (of +2 ionic charge) = (atomic mass) / (ionic or ion charge, which is +2 for sodium) = 23/2 = 11.5 mg. Therefore, sodium's conversion factor = 11.5mg per mEq.

Sodium-23 mass is 39.4% or NaCl or 0.394 as a ratio to salt (NaCl), since the ratio of atomic masses of sodium to a molecule of sodium chloride is 23/(23+35.4) = 0.394.

=> 27 August 2019 John B. Cook NaCl body mass = 114x11.5/0.394 = 3330 mg/litre

At 70% body water content and 70kg body mass, this equals 49kg of water = 49 litres water, so the total NaCl is 3330 x 70 = 233100 mg = 233 grams NaCl (total salt content).

Repeating this calculation with the ideal 140 mEq/litre sodium level in place of the measured 114 mEq/litre, gives (140/114)x233 = 286 grams NaCl as required amount.

Thus, the difference of 286-233 = 53 grams of NaCl is John Cook's NaCl deficiency, causing hospitalisation on 27 August 2019. This 53g deficiency is beyond a mere sprinkle of salt on a meal, and must be addressed gradually by balancing intake with loss. The needed extra salt daily to prevent a deficiency is the 53 g deficienty divided into duration of sodium in his body.

Duration of water and associated highly-water-soluble sodium is approximately given by the fact that the 49kg entire body water content is being excreted at the rate of about 2 litres (2 kg water) a day, i.e. a time period equal to (49kg)/(2kg/day) = 24.5 days. So the required NaCl extra intake per day he needs is = 53g/24.5days = 2.2 grams extra NaCl per day.

We are therefore trying to ensure that in addition to John's normal salt on meals, he takes an additional 0.5 gram of NaCl dissolved in every 0.5 litre glass of water (thus approx 2g per day of extra salt intake), to ensure that the high water flushing needed to prevent growing kidney stone infections doesn't cause acute hyponatraemia again.

We are also home-monitoring John's blood pressure (currently 125/80), to ensure that this extra approx 2g/day sodium chloride intake does not cause blood pressure problems. At present, it isn't. Urinary consultant Mr Maan stated in December that he cannot operate to remove the kidney stones during the covid-19 crisis, so John still needs regular prophylaxis trimethoprim antibiotics (nitrofuratoin has failed to prevent urinary infections 3 times), and plenty of water flushing to prevent kidney infections.

Apixaban was causing a severe skin allergic reaction/bleeds was finally replaced with the alternative anti-platelet clotting drug Clopidogrel which has totally stopped John's skin allergy and profuse skin bleeding, but then the GP insisted to John he take Apixaban again (as well as Clopidogrel), and his skin and urinary bleeding and anaemia problem resumed. This explains is why I am still so concerned over these "very technical nuts and bolts"! We have been reassured time and again that all will be well, and yet the medication problems have caused severe dizziness in John. (I was also prescribed medication but I control my high blood pressure using bananas, high in potassium, plus a blood pressure monitor to determine the correct banana dose by trial and error! So some of these observations might possibly be of more widespread interest than just to one patient, John.)

Kind regards,
Ann

From: England, Alyce <Alyce.England@esneft.nhs.uk>
Sent: 01 April 2021 17:16
To: 'johnbryancook@hotmail.com' <johnbryancook@hotmail.com>
Cc: PALS <PALS@esneft.nhs.uk>; Rasool, Iftikhar <IIftikhar.Rasool@esneft.nhs.uk>
Subject: RE: D'ARCY WARD, COLCHESTER HOSPITAL, DISCHARGE OF JOHN COOK b. 30/06/1933, NHS No. 4129440845

Dear Ann

Thank you for your enquiry we hope this email response finds you well. I have liaised with Dr Rasool (John's consultant) and we have discussed the responses to your questions detailed in your email.

1). John has had a chest examination today consisting of chest auscultation, there was no wheezing, no signs of fluid overload, reasonable air entry and saturations where 98% on room air and respiratory rate is 20 breaths per minute. Dr Rasool doesn't feel a repeat chest x-ray is indicated at this time based on clinical parameters. Repeat Chest X-Rays would be carried out if there were signs of clinical deterioration in breathing function despite treatment.

2). As discussed on the telephone we are unable to facilitate for ear suction as an Inpatient during an acute hospital stay, however if you are able to arrange for someone to be willing to carry this procedure out we are happy to accommodate for this to take place whilst John is on the ward.

3). After our discussion regarding the catheter I was advised that Johns catheter had come out (the balloon had deflated and fallen out). We have monitored Johns urinary passing and he is passing urine freely with no retention therefore a catheter has not been reinserted at this time.

4). Unfortunately whilst patients are in hospital it is not accessible for patients to receive a COVID vaccine as patients are required to be well physically and functionally, however Johns second COVID vaccine can be facilitated in the community by either district nurses who will visit patient homes if they are housebound or staff within the nursing home should this be his discharge destination.

We would also like to advise that John has been assessed by the physiotherapy team today and was able to sit on the edge of the bed well with assistance of one person and was able to stand on two occasions using a rotunda and assistance of 2 for around 3 seconds each time. They have recommended that we continue to support John to sit out in the chair as tolerated using the rotunda to transfer him from bed to chair. If he is unable to tolerate this we can consider the use of a full body hoist if he is not too fatigued to do so safely.

John has also been reviewed by the palliative consultant today who has also advised that John does appear to be very frail and may not improve following this admission as discussed yesterday with you, John will continue to be reviewed by the palliative team as required for symptom control if these arise.

I hope this email has answered your enquiries and offers some reassurance with regards to Johns on-going care whilst he is on Darcy ward. Please feel free to contact myself or Dr Rasool should you have any further enquiries or questions you would like answering.

Kind Regards & thanks

Alyce England
Ward Sister
Darcy Ward

Ext 5389

From: john cook <johnbryancook@hotmail.com>
Sent: 01 April 2021 07:15
To: Communications <Communications@esneft.nhs.uk>
Subject: D'ARCY WARD, COLCHESTER HOSPITAL, DISCHARGE OF JOHN COOK b. 30/06/1933, NHS No. 4129440845

Ann Cook, RGN (retired),
42 Pampas Close,
Highwoods,
Colchester,
Essex,
CO4 9ST

Sister Elise and Dr Ahamed,
D'Arcy Ward,
Gainsborough Wing,
Colchester Hospital,
Turner Road,
CO4 5JL, email communications@esneft.nhs.uk

Thursday 1 April 2021

Dear Sister Elise and Dr Ahamed,

RE: DISCHARGE OF JOHN COOK b. 30/06/1933, NHS No. 4129440845

Thanks for the call yesterday afternoon. To speed my decision up, please clarify:

(1) John is in discomfort and always needs to clear his chest of clear mucus after respiratory infections, before he is able to either eat or stand up because the mucus reduces his air access to lung surface area, which makes his pulse fast and causes him dizziness. I asked on the phone if John had a chest X-ray to check for residual fluids two weeks after his 18 March pneumonia, which our son has observed being coughed up as a clear mucus discharge in choking on his first sip of water? I asked this of you during the phone call, but I did not receive any answer (I checked the call again). Please clear John's lungs, and x-ray them to confirm the fluid has been removed.

(2) My son also asked Dr Ahamed yesterday if he will do us the courtesy to speed up John's discharge from your ward by allowing microsuction of the hardened wax in John's ears as soon as possible, as was attempted on the NHS when he was admitted to Birch Ward on 8 Dec 2020 – essential to communicate easily with John during any care at home or elsewhere. The wax in December was hard and couldn't be removed, so we were told to use olive oil ear spray and sodium bicarbonate ear spray to soften the wax and allow it to be removed by a subsequent NHS ENT microsuction. Hearing is vital to John, so because microsuction is only done in hospital, we request this be done as soon as possible, to speed up a safe and comfortable discharge, please. (We have a phone appointment with John's ENT consultant Mr Maheshwar for 3pm

today.) Please facilitate this as soon as possible so John can clearly hear us when we explain the situation and ask him for input into the decision, an important factor.

(3) I also asked if John's bladder cathether could be changed under local anaesthetic prior to discharge, as this was fitted on 5 Nov 2020, and has been overdue for change for three months now (because Colchester Hospital cancelled the appointment in January). It can't be done at home. Sister Elise agreed to do it in the call prior to discharge. Otherwise, it causes unnecessary infections.

(4) John is now overdue for his 2nd dose of the Pzifer covid Vaccine which must be given in hospital and cannot be given at home due to low temperature vaccine storage.

Kind regards,
Ann Cook, c/o johnbryancook@hotmail.com